

November 10, 2011  
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Compassion and Choices  
c/o Jennifer R. Levin, PhD  
Southern California End of Life Coordinator  
Compassion and Choices  
5042 Wilshire Blvd #16837  
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Dear Compassion and Choices,

My name is Colleen Kegg and I live in Santa Barbara, California. Recently I met with Jennifer Levin of Compassion and Choices and she suggested I document my feelings about the entire dying process we all face. I have been diagnosed with Cortical Basal Syndrome often referred to as CBD so I realize that I need to communicate my wishes while I can still think and communicate clearly. I have had this condition for somewhere between 1-3 years. The average length of life is said to be 6 years after diagnosis, but not enough is known about Cortical Basal Syndrome to be able to predict with any certainty how long it will take the disease to run its course. The later stages of this condition are particularly heinous and unpleasant, and include loss of muscle control of the arms and legs leading to "alien limb syndrome", loss of speech, loss of balance and sometimes dementia. Through the online support group I have heard what others in later stages of CBD are experiencing and I would like to avoid these later stages.

My ability to speak is already greatly impaired and in the later stages I will be unable to communicate my wishes in any meaningful way. I want to clearly document my wishes so that they may be carried out to the extent possible and to avoid any possibility of legal or emotional trouble later.

I would like it to be known that I have no intention of living life when real life is over. When I become that "tube" that takes in nutrition, excretes waste and requires help just to do it, I will not consider that living. When no hope of recovery or even improvement is offered by skilled medical personnel, I feel as though the decision is mine to decide the late actions in my life. In that vein, I want the option to legally control my time of death. This could be with a lethal injection if offered, a lethal cocktail if that is an option or other legal means such as Voluntary Stop Eating and Drinking or legal pain control measure that may have a possible side effect of death.

I have told relevant relatives and lots of friends and all support me. If they aren't the type to support me, I am reluctant to tell them. However I have met no resistance and lots of affirmation in my decision. My husband, Bob Simon knows. My sister Karen Kegg & her husband, Tim Johnson know. Countless friends in California, Texas and Washington DC have been told.

This is not a new concept for me. Rather, it is something that gelled a bit more with each passing year and passing death I lived through. The deaths of my 2 parents (6 and 12 years ago) were a large factor in discussions I began to have. I absolutely want to live well and happily as long as possible. But I am a strong believer in the reality that life is about quality, not quantity. When I feel like I only have a short time left and that that short time will be full of discomfort that brings on a longing to die, I plan to hasten death in whatever way legally allowed. I don't know now whether I will define that "short" time as 1 day, 1 week or 1 month but I'm pretty sure that CBD will prevent me from communicating in traditional ways so let it be known now that I fully intend to have a say in my own end. I intend to be able to make it known that it is MY decision and I have NO intention to bring harm or troubles to any person legally assisting me in this. Permission is hereby granted to let me, even help me go on MY terms.

Sincerely,  
Colleen Kegg